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Rehabilitation after gynecological cancer treatment

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1. Introduction

The burden of disease and treatment effects from gynecological cancer can cause significant distress in women as they begin to live longer with a chronic disease. Even where there are good outcomes in terms of cure, women have significant rehabilitation requirements. Those women entering the cancer survivor phase following treatment are likely to experience functional loss due to the physical and psychological effects of the disease, the treatment, and their personal processing of their cancer experience.

Rehabilitation to mitigate the distress-causing symptoms is as important a part of treatment as surgery, radiotherapy, or chemotherapy. For women with gynecological cancer we know that there is a complex interplay between the physiological and psychosocial symptoms, which means that rehabilitation itself is often complex and requires an integrative approach that treats the woman as a whole to achieve optimum success [1]. Rehabilitation is a key process within gynecological cancer care that begins with sensitive and specific assessments to identify a woman's functional level and the impairments that are impacting upon it so that effective targeted interventions can be implemented [2].

The aim of rehabilitation is to assist a woman to achieve the best possible level of function, to promote independence, and to adapt themselves to a "new normal" [3,4]. In their 2013 qualitative study interviewing women with gynecological and upper gastrointestinal tract cancers, Sandsund et al. [3] found that finding a new normal was an important aspect of their rehabilitation. This new state was attained through a process of adjustment to the changes in themselves and their relationships with others and the establishing new expectations about their life as a cancer survivor. Within the field of gynecological cancer it is now recognized that measuring the success of treatment by focusing on tumor response and survival is not sufficient and that patient-reported outcomes that describe quality of life are clinically meaningful [5].

2. Patient assessment

Increasing opportunities for rehabilitation to treat the complex symptoms are now being recognized. Inevitably, though, these opportunities may be missed where poor communication and inadequate assessment of the woman following treatment occurs [6]. Outpatient consultations can appear rushed, with women aware that the clinician has limited time. In an environment where there is a focus on determining recurrence, symptoms may be missed, especially where they cause embarrassment—such as sexual dysfunction, incontinence, or psychological distress—and a patient may be reluctant to spontaneously report their concern.

Gynecological cancer services that incorporate a screen and assessment tool within routine clinical practice allow women to identify and communicate with their health provider the symptoms affecting their well-being. Paul and Buschbacher [7] highlight the recommendation in the Institute of Medicine's report "From Cancer Patient to Cancer Survivor: Lost in Transition" that assessment tools and screening instruments need to be systematically developed and evidence based. If they are to be utilized in clinical practice, the tools also need to be practical, and sensitive and specific to each patient's cancer, symptoms, and functional needs. This creates the challenge that a tool developed to be sensitive and specific to the experience of women in one setting may not necessarily meet the needs of women from another. For instance the outcomes assessed by a tool designed in a high-resource country may not be suitable to be used in a low-resource clinical setting.

The literature describes the development of a number of patient outcome measures that have engaged women with gynecological cancer to describe and prioritize their most concerning symptoms. This engagement ensures that the measures are patient centered to better detect the symptoms, grade the severity, and assist in determining the best rehabilitation interventions and if rehabilitation efforts have been effective over time [5,6]. The QuEST–GY assessment tool [8] was developed in the UK for all gynecological cancer patients receiving outpatient chemotherapy to reflect actual clinical practice. It was developed by comparing issues raised by women in oncology consultations and those issues in existing validated instruments. Subsequent interviews with women with gynecological cancer and cancer clinical experts allowed the items to be prioritized. One important domain that has an impact on quality of life and is amenable to rehabilitation efforts is sexual function. Interviews with clinicians confirmed their concerns about assessing sexual dysfunction; however, patient interviews endorsed this as a significant issue that should be included on assessment tools, albeit with a clear option for the recipient to leave blank if desired [8].

The NFOSI-18 tool [5] was developed in the USA for use in clinical practice and specifically assesses patient-reported outcomes for women with ovarian cancer. Again, the measures in this tool were derived by a series of interviews with women with ovarian cancer and oncology clinicians. Jensen et al. [5] promote that the NFOSI-18 tool is likely to be more sensitive to identifying the physical, functional, and psychosocial symptoms associated with ovarian cancer and the

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treatment modalities, and better able to assess improvements in these in response to rehabilitation interventions.

3. Information needs

The continuous changes in symptoms as they transition through treatments and disease progression can leave women distressed by the uncertainty and unpredictability in their lives. A significant strategy within any rehabilitation program or intervention is to facilitate patients having a sense of control, which can prove a great coping mechanism and motivation to adhere to a rehabilitation intervention [9]. Information about what to expect, who they can contact, and resources available to them is integral to self-management and regaining control over their health [10,11]. The information they receive with regard to their symptoms and the rehabilitation strategies to address them needs to be consistent, timely, and tailored to the individual [12].

3.1. Consistency of information

Issues of consistency of information are often highlighted by authors describing rehabilitation to prevent vaginal stenosis after pelvic radiotherapy [12–14]. Miles and Johnson [15] in their 2014 update of a Cochrane Review into vaginal dilator therapy concluded that there is no reliable evidence supporting dilator therapy during radiotherapy treatment, and while several observational studies of dilator therapy after radiotherapy treatment suggest an association between frequent dilator therapy and a reduction in self-reported stenosis, they acknowledge that there is no proof that a decrease in stenosis is an effect of the dilator therapy. With no clear evidence as to the benefit of a rehabilitation therapy, there is inevitably a range of recommendations and advice given to patients [14].

Where advice is inconsistent a woman may struggle to motivate herself to comply with an intervention that she may perceive to be unpleasant. A number of clinical practice guidelines for vaginal dilator therapy have been developed, which is important to ensure consistency of advice within an organization. Bakker et al. [12] in the development of a guideline were motivated by the need to gain a consensus on recommendations for patients as to timing after completion of radiotherapy; how to practice dilator therapy including duration, frequency, and size of dilators; how information may be tailored to specific patient groups; and finally who is most appropriate to deliver counselling and support for this intervention [12].

3.2. Timing of information

Many authors argue that it may be appropriate to deliver information about rehabilitation prior to acute treatments [13]. Juraskova et al. [16] examined sexual adjustment following treatment for cervical and endometrial cancer and argued that the advantage in raising issues of sexuality and sexual dysfunction prior to commencement of treatment is that it lays the foundation for subsequent consultations and ensures that the patient is not unprepared for symptoms impacting on their sexuality and body image. In their interviews of women they identified that women were better able to cope with planned treatment procedures for which they had been prepared for compared with unexpected symptoms. They proposed that the patients' coping was affected by their sense of control that came from being aware and prepared for an event [16].

Cullen et al. [13] interviewed women to understand their perspectives on vaginal dilator therapy and one of their care recommendations was to introduce the vaginal dilator early on in treatment. Women revealed that if vaginal dilator therapy was mentioned prior to commencement of radiotherapy it was not discussed sufficiently for them to remember the plan for this rehabilitation therapy following treatment. Those women who were unprepared for this next step felt disappointed that their treatment was not over, which resulted in a negative attitude to the therapy.

3.3. Tailored information

Bonner et al. [14] interviewed women to assess their perception of vaginal dilator use and found that many women believed it would have been beneficial to receive a separate consultation with a nurse about how to manage this therapy so that they were not overloaded with information and would have an opportunity to discuss their particular concerns. Cullen et al. [13] stressed that the implementation of vaginal dilator therapy for a woman requires an understanding of her relationship with her body and her sexuality in order to understand her acceptance of it as therapy. A discussion that directly addresses any embarrassment or emotional issues associated with the symptom or the rehabilitation therapy can assist the woman to change her perceptions and values of the treatment; in the case of vaginal dilators she may come to see it as part of her ongoing medical treatment rather than as a sexual aid [13,14].

The intervention described by Schofield et al. [9], to address the psychosocial needs of women undergoing radiotherapy utilizing a nurse-led tailored consultation together with peer support to deliver information and self-care strategies to optimize their recovery, exemplifies these principles. Nurses providing consultations to deliver an evidence-based intervention receive training in key areas including communication, psychosexual care and rehabilitation, patient education, and distress management. This intervention is to commence prior to acute treatment to assist a patient to prepare for treatment, but also to discuss vaginal health and psychosexual rehabilitation and incorporating coaching and practice of self-care strategies. Subsequent nurse-led consultations during and on completion of treatment consolidate this teaching and support the patient with further exploration of the woman's individual experience. The woman is provided with a documented survivorship care plan describing the diagnosis and treatment, follow-up plan, and description of adverse effects and their management. A final telephone consultation with the nurse two weeks after completion of the treatment seeks to address the sense of abandonment often described by women at this time. The nurse discusses with the patient their experience of utilizing self-care strategies including use of vaginal dilators to promote optimal rehabilitation [9]. The effectiveness of this program to deliver timely and tailored information, psychosocial support through treatment, and engagement with vaginal dilator therapy is currently being studied in a randomized controlled trial—the PeNTAGOn study—comparing it with usual care [9].

4. Control and self-management

Rehabilitation interventions are designed to maximize the ability of a woman to gain control and self-management over her health. Rehabilitation interventions should not just focus on what health-related behavior is required, such as exercise, pelvic floor training, or vaginal dilator therapy, but also on the development of the woman's ability to self-manage. This sense of control can be extremely motivating, which makes adherence to a rehabilitative regime much more likely. Donnelly et al. [17] reported on women's experience of participating in a home-based physical activity intervention randomized controlled trial and found that a patient's own motivation was an important determinant of their compliance with an exercise intervention. The design of home-based interventions allows women from rural and regional locations to participate, and also gives the woman control of when and how she engages in her own rehabilitation [17].

Motivation is fed by the ability to see the results of the intervention; thus, it is important that measurable results that can be given to the patient are part of the design of a rehabilitation strategy. For a woman to maintain long-term vaginal dilator therapy she can be motivated to continue if at consultation she feels that the examination is easier and the

clinician advises her about stenosis [14]. Those engaged in an exercise program to improve their health, performance status, and symptoms of fatigue may be motivated by objective measures of their improved ability using pedometers and diarizing their progress [18]. Including feedback into rehabilitation therapy can be reassuring of improvements when it is positive and motivational for greater efforts or compliance when the feedback shows that further improvement is possible. Of course there are some for whom negative results can be demoralizing and demotivating, therefore it is important that feedback is given sensitively with counselling and support available to the woman.

Peer support is also reported by many women as an effective component of rehabilitation therapies. The support and education provided by the health professional can be enhanced by the provision of peer support. For women with gynecological and upper gastrointestinal tract cancer, Sandsund et al. [3] found that peer support offered these women understanding and empathy that they appreciated "on a practical and emotional level as it was sought by that individual at a time when the participant was receptive to exchange or receive support" [3]. In their design of a rehabilitation intervention during and after radiotherapy, Schofield et al. [9] used a multimodal design that incorporates nurse and peer-led support. In this intervention a peer contacts women after they have had a consultation with the nurse before, during, and on completion of radiotherapy and during the immediate recovery period. The peer's role is to provide psychosocial support allowing the patient to describe their story and to assist them in normalizing this. They are also trained to appropriately reinforce information about the self-care strategies and to refer back to the nurse where required [9].

Significant psychosocial distress is known to be experienced by those living with cancer, but for women with gynecological cancer there can be further impacts on their sexuality, body image, and social relationships, which are compounded by issues of menopause, fertility, bowel and bladder function, and sexual dysfunction. As women face an anxious and uncertain future following treatment, the psychological impact of the disease and treatment may be more apparent in the survivorship phase [3].

Anxiety and lack of control play on each other, which affects the patient's perception of the symptoms and capacity to adapt and find a new normal [3]. In their interviews with women with ovarian cancer, Jensen et al. [5] identified that several psychosocial symptoms were prioritized, including worry that their health would get worse, and their ability to sleep well and to enjoy life. Increasingly this complexity is recognized by looking at symptom clusters rather than at each symptom in isolation. Lopez et al. [19] took a qualitative approach using patient narratives over four time points to identify symptom clusters in women with gynecological cancer. The most common symptom cluster was fatigue, sleep disturbance, pain, and depression [19].

Gynecological cancer rehabilitation has started to include interventions that target this symptom cluster by utilizing exercise to achieve psychological and physical benefits for women. Donnelly et al. [17], in a follow-up to their randomized controlled trial testing the feasibility and efficacy of a home-based physical activity behavioral change intervention, interviewed participants to gain an understanding of their experience. While the physical symptom of fatigue showed improvement at least initially by participation in exercise, it was psychological improvement that was experienced by all participants. Recognizing this, and in response to the participants' suggestions for improvement to the program, the authors propose a multidimensional intervention that offers more than an exercise program but also includes supportive care strategies that address healthy lifestyle, coping with uncertainty, and social support needs [17].

5. Conclusion

Rehabilitation following treatment for gynecological cancer helps women adjust to their changed condition by effectively preventing or mitigating the symptoms related to their cancer and its treatment [20]. Strategies that ensure sensitive enquiry within clinical practice into the physical, psychosocial, and functional symptoms that women with gynecological cancer find most distressing are an important first step in facilitating recovery. Preparing the patient with timely, consistent, and tailored information addresses their anxiety about the unknown and can support them to take control of their lives again. The development of multidimensional rehabilitation interventions that are flexible both in how and when they are undertaken and that treat the patient as a whole by integrating the physical, psychosocial, and behavioral aspects of the symptom experience is the future for gynecological cancer rehabilitation.

Conflict of interest

The author has no conflicts of interest to declare.

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